Bless you! Girl who kept sneezing has stopped

By Mike Celizic TODAY contributor 2/28/2013 11:23:53 PM +00:00

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The most remarkable thing Lauren Johnson did Wednesday morning was — nothing.

During two previous visits to TODAY's New York studios, the shy 12-year-old sat on a couch and sneezed and sneezed and sneezed. The achoos came at the rate of up to 12 a minute and 12,000 a day, pausing only when she fell into the deepest phases of sleep.

But Wednesday Lauren sat quietly, her hands clasped between her knees as she listened to her mother and two doctors talk with TODAY's Natalie Morales about the strange disease she had that made her sneeze continuously for four months, and how it was brought under control.

"How are you feeling?" Morales asked.

"A lot better," Lauren said politely.

Her mother, Lynn Johnson, took over from there.

"Two weeks ago, it stopped gradually over a two-day period," she said.

No more 'achoo'

For that, Lauren has Dr. Denis Bouboulis to thank. An allergist and immunologist, Bouboulis realized that Lauren had a rare and only recently identified condition called PANDAS. That's not a reference to the cute Chinese bears; instead it's a complicated acronym for pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections.

What it means in layman's terms is that in the process of fighting a strep throat infection, Lauren's immune system went haywire, producing antibodies that ended up migrating to her brain and attacking her own tissue. The disorder can cause tics and obsessive-compulsive behavior — or, in Lauren's case, nonstop sneezing.

Lauren's sneezing started last October, and she was on TODAY in November. At the time, she had been seen by a half-dozen doctors and other health professionals and was in the process of undergoing virtually every test known to medical science.

But no one could put a finger on what was causing her sneezing. At the time, NBC's chief medical editor, Dr. Nancy Snyderman, speculated that there could be a psychosomatic aspect to it.

'Body turns on itself'

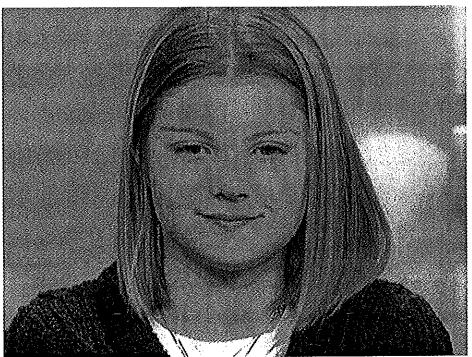
There is no clinical test for PANDAS; Bouboulis arrived at his diagnosis by running through a checklist of symptoms. The treatment for the syndrome is called IVIG, which stands for intravenous immunoglobulin. The treatment bolsters the victim's immune system, allowing it to fight off the invaders.

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"The underlying theme is a bacterial infection that triggers almost a hyperreaction in the body," Snyderman explained. "And then the body sort of turns on itself when your immune system sees itself as foreign."

"There is molecular mimicry," Bouboulis agreed, expanding on Snyderman's comments. "There are proteins on the strep that generate an immune response. These antibodies mistakenly think that certain brain tissue is actually strep."

Bouboulis gave Lauren two days of IVIG treatments. After the first day, the sneezing diminished. After the second, it stopped.



Though her mother says Lauren is "not cured," the 12-year-old did not sneeze on TODAY Thursday — a dramatic contrast from her previous appearances on the show.

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But Lauren and her mother's relief is tempered by the knowledge that there is no cure for PANDAS. The sneezing could return with a future strep infection.

"She's not cured," Lynn told Morales. "That's the biggest problem with this disease. Parents live in fear because they can be reexposed to bacteria, including strep, and re-manifest again. Some children go years and some children go months. Some children never re-manifest again."

Lynn said the reason she came on TODAY is to help educate others about this littleunderstood syndrome and to encourage medical investigation into it.

"We need to learn more about it," she said. "We need more research."

For more information about PANDAS, click here to visit the PANDAS Resource Network.

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PANDAS and **PANS**

Re: SB 360 An Act Concerning PANDAS

It is our responsibility to seize every opportunity to prevent the devastating effects of mental and neurological illnesses. Recent research has demonstrated genetic vulnerabilities, infections and immune processes are a significant cause of many mental and neurological illnesses. One immune process causing mental illness in called autoimmunity which starts with infectious agents having molecules similar to those within the brain. Immune reactions against the infection result in antibodies attacking the brain which can cause a spectrum of behavioral, mental, cognitive and neurological symptoms.

I have treated thousands of patients who have had infections causing adverse mental symptoms and have written journal articles and given presentations on infections and their immune effects causing a broad spectrum of symptoms including autism spectrum disorders, psychiatric symptoms, seizures, violence and other impairments. Patients with PANDAS and PANS are sometimes haunted by intrusive and sometimes horrific thoughts.

It is important to advance awareness for the public, physician and educators; to support clinically relevant research; to develop early intervention strategies; to crate plans to deal with insurance company and other obstacles to access to care and to develop an effective advisory committee. In the wake of Newtown, Connecticut and the Nation have made a commitment to better understand and prevent mental impairments that are harmful both to the individual and to our society. Let's fulfill that commitment by looking at each potential contributor and let's reduce the burden of disease that PANDAS, PANS and other mental illnesses adversely impact us.

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